



Muscular Dystrophy
New Zealand



STRATEGIC PLAN





Strategic Plan

About Us

The Muscular Dystrophy Association of New Zealand Inc. (MDANZ) began in the late 1950's as a support group for families affected by muscular dystrophy. Since then, MDANZ has broadened its scope to include many other neuromuscular conditions. We are proud to have Judy Bailey and Dame Susan Devoy as our longstanding patrons.

Our logo is a person shown in the form of DNA. This double helix represents the genetic component to many of our conditions and reflects our commitment to families and the acknowledgement of whakapapa or family histories, which are woven through the stories of our members. Our unique governance structure ensures leadership of the organisation by individuals or family members with lived experience of a neuromuscular condition.

We have four regional branches that are supported by the national office based in Auckland. MDANZ supports individuals, families and whānau by providing specialist information, practical resources, personalised support services, social networks, campaigns for public awareness

and advocacy. And through our research trust, we work to improve care standards and facilitate access to potential treatments for neuromuscular conditions.

Our organisation is a registered charity and we rely almost entirely on voluntary donations from the general public, trusts and other businesses/organisations to continue our work.

Our vision to the year 2020

Iti rearea teitei kahikatea, Ka taea!

Even the smallest bellbird, the rearea can ascend the great heights of the kahikatea tree.

This whakataukī (proverb) from Tūhoe has inspired an organisational waiata (song) and is referenced in the illustrations chosen to present the strategic plan for the Muscular Dystrophy Association of New Zealand Incorporated. We thank all contributions to this important work.



Vision

Freedom beyond limits

Mission

Promoting freedom of choice
and a responsive society

Values

Sustainable Toitūtanga
Empowering Whakamanatanga
Proactive Kōkiritanga
Connected Tūhonotanga

2020 Vision

The Muscular Dystrophy Association of New Zealand (MDANZ), is a unique member-led organisation that will deliver life changing impact to people living with neuromuscular conditions and their communities of support so that they may enjoy freedom beyond limits. Strategic priorities will be developed in alignment with this framework and all operational activities will be a manifest of the vision, mission and values of the organisation.

We will ensure our activities and outcomes are:

Sustainable - Toitūtanga

We are committed to sustainable leadership, continuous learning, innovation and collaboration.

Empowering - Whakamanatanga

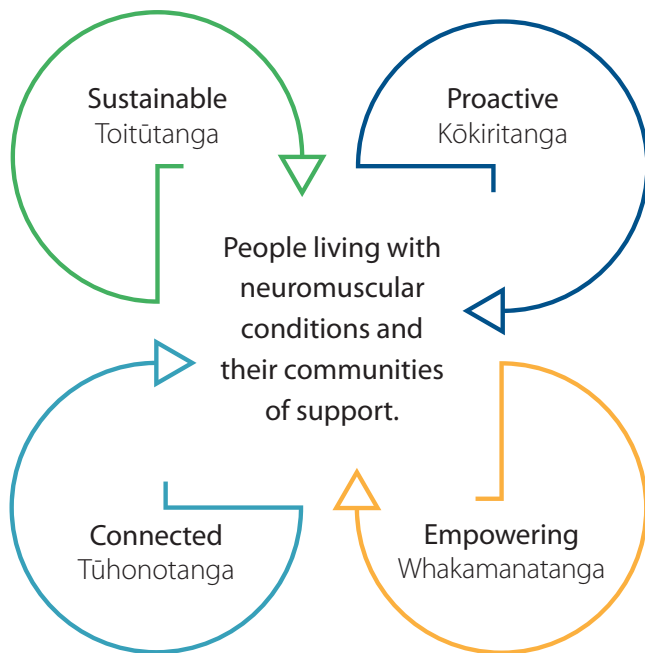
We will work in partnership to create opportunities for people living with neuromuscular conditions to enjoy more freedom and participate successfully in life.

Proactive - Kōkiritanga

We will facilitate social change and research. We will proactively identify priority populations and target our resources to make an even bigger difference.

Connected - Tūhonotanga

We value the role of whānau and communities. We foster collective awareness and strong relationships.

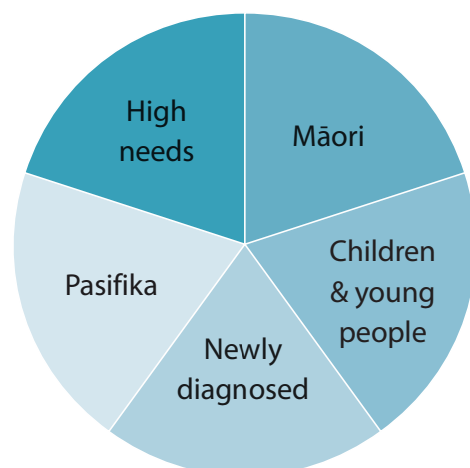


1. Identifying the volume of service delivery
 2. Surveying our members and other service users to evaluate level of satisfaction with services delivered
 3. Developing questions and measures to evaluate what benefit people have derived from our services
- Evaluation measures will be developed and refined on a regular basis as part of the annual planning process, to ensure we are a responsive and agile organisation.



Priority populations

Neuromuscular conditions can affect people of all ages and all ethnicities and the information and support offered by MDANZ is available to all members. However, there are certain groups of people who have been identified as needing a priority focus due to specific needs or health inequalities. These groups are outlined below.



We will create life-changing impact by:

- Engagement and connection with our members and their communities of support
- Ensuring access to current and accurate information on neuromuscular conditions and enablers for independence
- Creating opportunities for our members to exercise their full rights of citizenship
- Improving access to life enhancing resources, from both government and non-government sources
- Advocating for best practice in approaches to care and treatment for people with neuromuscular conditions
- Working in partnership to provide individualised support and advocacy
- Facilitating research and fostering communities of practice
- Committing to grow the resilience and capability of our members, and their families and whānau

We will measure success by:

- Developing an evaluation framework based on a results based accountability (RBA) methodology; this will include (but may not be limited to):

- Members with high needs may require greater assistance to achieve well-being, access resources and participate. This group is prioritised in recognition of the specific challenges of living with a progressive condition.
- Māori are the Tangata Whenua of New Zealand (indigenous people of the land), and experience greater disparities than other New Zealanders. For this reason, the New Zealand government recognises the importance of culturally responsive health and disability services as well as initiatives, to improve health gains for Māori.
- Children and young people are vulnerable, particularly at points of transition. By prioritising early support for children, young people, their families and whānau, we can help to build resilience, establish social resources and links with appropriate services, in order to improve outcomes and quality of life.
- People newly diagnosed have a high need for information, practical support and facilitated opportunities to link with others who may have a shared experience. This is a known time of grief and vulnerability for individuals, their families and whānau, and is therefore a priority area for service.
- Pasifika people also experience health disparities when compared with other New Zealanders. Reducing barriers for Tangata Pasifika to receive information and support is therefore an important aim.

In identifying priority populations, we are providing ourselves with a compass for decision making and an important tool for fundraising initiatives. This becomes most important when we have to prioritise - e.g. when resources are constrained and/or for the targeting of resources to achieve equity for a sub-group of our broader membership whose needs are not well met by mainstream approaches.



Statement of intent

In adopting this strategic framework, the governing body (National Council) and the Chief Executive of MDANZ commit to its intent and are collectively responsible for service delivery that aligns with our core values and takes us ever closer to the stated vision.

This framework implies inclusive and collective involvement in the revitalisation of our organisation for the benefit of its members and their communities of support.

Organisational waiata (song)

**E rere
ki hea
puta atu
rere tonu.**

*True freedom is within, to live
beyond our limits, and rise above
challenges, with perseverance
and commitment.*

**Iti rearea
kahikatea
ka taea
ka taea.**

*Like the tiny rearea bird, whose
size is no limit, to it standing a top
the tall kahikatea, we soar on the
wings of freedom.*